

How to reduce stigma in leprosy – a systematic literature review

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Summary

Background: Interventions to reduce leprosy-related stigma reduce the manifestations of stigma that cause so much suffering to individuals and their families.

Purpose: This systematic review aims to identify interventions that have been used to reduce such stigma and to summarise what is known about their efficacy.

Method: Electronic searches were undertaken using PubMed (Medline), CINAHL and PsycInfo databases. The internet was searched using Google Scholar for papers not published in these databases. All relevant papers written in Thai or English were included.

Results: After reading 55 papers, three duplications and parallel literatures were removed, 18 were removed on abstract screening and nine after reading the full papers; eventually, 25 were included in this review. Interventions with some evidence of effectiveness in terms of stigma reduction comprise the integration of leprosy programmes into general health care; Information Education and Communication (IEC) programmes; and socio-economic rehabilitation.

Conclusion: More evaluations are needed of the effect of the integration of leprosy programmes into general health services. The design and implementation of IEC interventions need to be preceded by careful study of the target area and population and should be undertaken in combination with other activities.

Introduction

Society has stigmatised people affected leprosy since ancient times.¹ It manifested in various forms, ranging from compulsory identification of leprosy patients with special clothing or by ringing bells when approaching others; restriction to begging as the only means of subsistence; and measures of forced segregation.¹ More formal segregation has been practised since the 13th century when leprosy occurrence reached pandemic proportions

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during the Crusades.² Also the treatment and care of leprosy patients usually occurred in separate institutions. After the discovery of dapsone in the 1940s, there was a gradual shift to outpatient care.³ In 1982, the World Health Organization declared that leprosy was curable.⁴ Although compulsory institutional segregation is now a thing of the past and leprosy is curable, stigma is still widespread across the world.^{5–10}

When diagnosed with leprosy, patients often try to conceal the disease, for example by seeking treatment from a health centre at some distance from their home.⁸ To avoid negative behaviour from their community, leprosy patients and, on occasion, their spouses may withdraw from communication with other members of their community.^{7–9} In addition to self-isolation practiced by leprosy patients, community members also express their negative attitudes by avoiding them, forcing them to leave, gossiping about them, and refusing to share public transport with them.^{a,b,6} Such behaviours have a negative impact on the physical, psychological and socio-economic status of people affected by leprosy. Psychologically, they may suffer mental stress and anxiety leading to depression and even, in some cases, suicide.^{9,11} In many cases, their economic situation may decline, their marital partner may reject them, and opportunities for further education may be reduced.

To prevent stigma and to reduce the manifestations that cause so much suffering to individuals and their families, effective interventions are needed. This systematic review aims to identify interventions that have been used to reduce such stigma and to assess their efficacy. The results of this review will be useful for health personnel and other professionals who wish to develop interventions to address leprosy-related stigma.

Methods

Electronic searches were undertaken using PubMed (Medline), Cumulative Index to Nursing and Allied Health (CINAHL) and PsycInfo databases with the search term ‘leprosy AND (stigma or discrimination) AND (intervention or IEC or CBR or counselling)’. The internet was searched using Google Scholar for papers not published in the mentioned databases. Draft reports and instruments were retrieved from collaborating partners of the International Consortium for Research and Action against health-related Stigma (ICRAAS). Hand searching was also done for unpublished literature, relevant newspaper articles, theses, conference proceedings and reports. Studies included were those written in Thai or English, using qualitative, quantitative, or mixed methods. All publication years were included.

Results

Figure 1 shows the process and numbers of publications identified, screened and eventually included in the review. After reading 55 papers, three duplicates and parallel literatures were removed, 18 were removed on abstract screening and nine after reading the full papers; eventually, 25 were included in this review. The papers included were written between 1989 and 2010. The findings are presented in narrative form. Interventions implemented to reduce leprosy

^aNontanum B. Social-psyco problem of self-isolating leprosy patients. Nakhon Sawan, Thailand: Regional Office of Disease Prevention and Control 8; 2008.

^bPredaswat P. KhiThut, “The disease of social loathing.” An anthropology of the stigma in rural Northeast Thailand” [PhD thesis]. University of California; 1992.

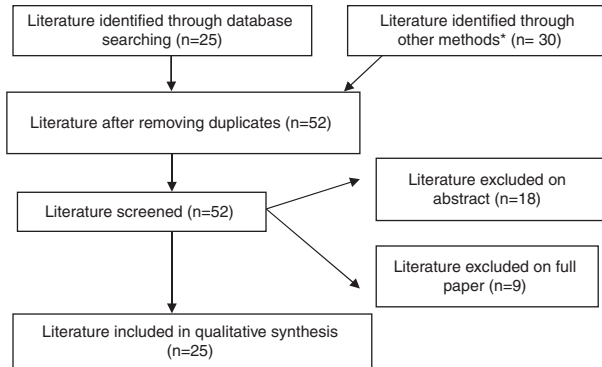


Figure 1. Flow diagram of identified papers by database searching. * *Hand searching and searching using Google Scholar*

stigma are presented in five categories: integration of leprosy services in general health care; Information, Education and Communication (IEC) programmes; socio-economic rehabilitation (SER); changing the name of the disease; and counselling. The geographical coverage of the studies includes countries from Africa, Asia and Latin America in which leprosy is endemic.

CATEGORIES OF INTERVENTIONS TO REDUCE STIGMA

Integrated services

In many countries, leprosy services have been integrated into general health services, aiming to provide care for leprosy patients near to their homes and to reduce the feeling of difference between leprosy patients and those with other diseases.^c A study conducted in Maharashtra, India, compared stigma levels between areas with integrated and vertical care approaches to leprosy control.¹² It established there was less self-stigmatisation among leprosy patients and less social stigma in communities where leprosy was integrated into general health services. Moreover; leprosy patients and their families were involved in decision making in areas with an integrated approach, while in areas with a vertical-approach they were not consulted.

Following trends in the international community, leprosy services in Thailand have gradually been integrated into the general health care system since 1973. This process was completed in 1998.^d However; the monitoring and evaluation report of the National Leprosy Elimination Plan (1994-1996) did not mention whether leprosy-related stigma had decreased, despite the fact that enabling people affected by leprosy to live with dignity in the 'normal community' was the major objective of the Plan.^e

INFORMATION, EDUCATION AND COMMUNICATION (IEC)

IEC is an approach used to raise the general population's awareness of leprosy, aiming to reduce stigma, and to encourage people who suspect that they may have contracted leprosy to report early to a health unit before developing disability. The social marketing campaign undertaken in Sri Lanka is an example of a successful IEC intervention.¹³ It was launched in

^cCharoon P. Leprosy profile. Bangkok: Leprosy Division; 1995.

^dRaj Pracha Samasai Institute. Leprosy in Thailand. 2006 May 15; word file. 2006.

^eLeprosy Division. Annual report. Bangkok: Thamasart University; 1999.

1990, encouraging people with suspicious skin lesions to seek diagnosis and also aiming to change the negative attitudes of the general population towards leprosy. Health providers were trained to diagnose leprosy and to refer persons with suspicious lesions to leprosy staff. The costs of seeking care, such as bus fares and lost wages, were reduced by improving the network of clinics. In addition; public health messages were conveyed using different media, informing people that leprosy is a 'normal' disease that can be cured and does not necessarily lead to disability if treatment is sought early. Before creating the content of messages, the campaign undertook community-based surveys on knowledge, attitudes and practices related to leprosy, as well as focus groups to explore public perceptions of leprosy. These rounds of consultation established that leprosy was perceived to be an extremely infectious, incurable and dreaded disease that caused fingers to fall off. This information was used to develop targeted IEC materials. After less than a year, newly detected cases increased by 150% with a dramatic increase in self-reporting. Approximately every second person sought treatment on their own initiative, compared to less than one in ten in the past.

This kind of approach was also adopted to promote early treatment and reduce stigma in Uttar Pradesh, Madhya Pradesh, Orissa, Bihar and West Bengal, India. In 1999, a 16-month intervention was launched using television, radio, live drama shows, video, screening vans and public events for information dissemination.¹⁴ As a result of this intervention, the proportion of people who said they would not sit next to a leprosy patient fell from 44% to 27%, as did the proportion who would not eat food prepared by a leprosy patient (from 68% to 50%).¹⁴ In addition, the proportion who believed that leprosy was caused by bad deeds in a previous life fell from 37% to 12%. A study conducted in Bangladesh compared a group who had received health education about leprosy with a group who had not.¹⁴ Seventy-eight percent of the latter would not buy goods from a shopkeeper known to have leprosy, compared with 25% of the group who had received health education.¹

Despite these positive cases, IEC activities do not always change attitudes to leprosy in the desired direction. For example, some children became less tolerant of leprosy after a health education session about leprosy at school in South India.¹⁴ Other studies have shown that improved knowledge of the ability to cure the diseases did not change negative attitudes towards leprosy patients.¹⁵ It has been suggested that fear of leprosy makes it difficult to educate the public about the disease.¹⁴ Some community leaders suggest that changing attitudes is a huge task because leprosy remains a taboo subject.¹⁴ For this reason, it is seen as a disease of society, not of people.¹⁴

The Thai Leprosy Control Programme (TLCP) carried out four IEC campaigns between 1996 and 2007 as a major part of the Leprosy Elimination Campaigns conducted to observe various special occasions of the present King, His Majesty King Bhumibol Adulyadej, who kindly supported the TLCP since the beginning. It was expected that the messages regarding leprosy cure and free treatment would end the public's fear of leprosy and promote early case detection.¹⁶ Dissemination of knowledge was conducted at national, regional and provincial levels through leaflets, television, posters, radio, local performances, and village radio announcements. Moreover, monetary incentives were given to new cases and to those who suggested to persons suspected of having leprosy to go for examination and diagnosis. After the first three campaigns, the number of newly detected cases had increased by 20%, while the number of newly detected cases in subsequent campaigns decreased. There is no record whether the stigma attached to leprosy had changed as a result of the campaigns.^f

^fRaj PrachaSamasai Institute. Evaluation of 2005 Leprosy Elimination Campaigns. Nonthaburi 2009.

SOCIO-ECONOMIC REHABILITATION

To empower self-reliance, social-economic rehabilitation (SER) has been launched in many leprosy programmes. In Southern Nepal, Cross & Choudhary launched the Stigma Elimination Project (STEP) in 2002.¹⁷ The project started by appointing 10 people affected by leprosy to act as facilitators to develop self-care groups in their villages. These people had attended self-care training, a core feature of the programme run by the Nepal Leprosy Trust (NLT). After the training, the facilitators were assigned to encourage people affected by leprosy in their village to establish self-care groups with the primary objective of controlling impairment. After one year, the groups took on the form of self-help groups for credit and micro enterprise development and had expanded their membership to include other marginalised people. The groups contributed to the development of their communities. The effectiveness of the programme was confirmed by measuring the level of social participation reported by the members of the group. The STEP participants had significantly higher levels of participation compared with controls that had not been part of the intervention and their levels of social participation were higher than would be expected even for the general population. In addition, leprosy-affected people without visible signs or ulceration (whether in STEP group or not) did not appear to suffer participation restriction.

In 2006, Ebenso *et al.* studied the impact of SER on leprosy stigma in five northern states of Nigeria.¹⁸ A set of quantitative questionnaires and semi-structured interviews were conducted with 20 randomly selected SER participants. Five focus group discussions and 10 key informant interviews were also conducted to complement individual interviews. SER was found to improve self-esteem, financial independence, acquisition of new skills, and access to public institutions. SER also influenced the process of social integration, resulting in a positive attitudinal change towards SER participants.

In Thailand, during the period July 1998 to June 2000, a study was launched to develop an appropriate model for community-based rehabilitation (CBR) and improve the quality of life of people affected by leprosy.⁶ The research was undertaken in two phases. In the first phase, a research team spent three months in the community using anthropological tools to collect relevant information. People affected by leprosy were found to encounter different levels of stigmatisation according to their relationships with relatives and friends, disability status, and social-economic status. In the second phase, the team encouraged local people to establish CBR through participatory identification and analysis of the problems of people affected by leprosy and of other people with other disabilities. They participated in planning and in implementing rehabilitation activities.⁶ These activities included: a disability survey, taking people with disabilities to hospital, registering people with disability in order to be eligible for government assistance, raising funds, organising stores where people with disability worked as shopkeepers, and establishing disability development centres. However, the effect of the intervention on stigma reduction was not assessed.⁶

CHANGING THE NAME OF THE DISEASE

As the term 'leprosy' may lead to discrimination, there were attempts to change the name to Hansen's disease after the Norwegian medical scientist who discovered *Mycobacterium leprae*.³ Zen-Ryo-Kyo, the National Hansen's Disease Sanatoria Residents' Association of Japan, began to promote the new term in 1952.¹⁹ The term was gradually accepted and Japan's mass media started using 'Hansen's disease' in the mid-1960s. By the end of the

1970s, the word 'leprosy' had been mostly abandoned in Japan.¹⁹ In Brazil, the word 'lepra' which means 'dog mange', is discouraged by law.¹⁵ However, people are often aware that leprosy and Hansen's disease are the same disease.¹⁴ In Thailand, an attempt to change the name 'leprosy' to be 'Numbness skin disease' was initiated at a meeting of leprosy workers at national and regional levels in 2003.^g The new name was used by some regional leprosy programme in IEC campaigns. The 'Leprosy clinic' of the National Leprosy Organisation changed its name to 'Numbness skin disease clinic'. There is no evidence to show to what extent the new name has changed attitudes towards leprosy.

COUNSELLING

Counselling may help people affected by leprosy to cope with physical and psychological effects of the disease. A pilot study of group counselling for people affected by leprosy was conducted in Nepal from 1994 to 1998.²⁰ Groups composed of 5-7 individuals meet for 2-hour sessions for 5 weeks. They met as single-gender adult or children's groups. Patients were included after a psychological assessment in which they had demonstrated at least one of the following: their own recognition that their low self-esteem is due to stigmatisation, rejection by their families, or that they were despondent but not clinically depressed. Participants were encouraged to share their life stories with the other members of the group. This developed bonds between group members as they heard others tell about their own painful experiences and they could comfort each other. The patients learned to forgive other people who hurt them, and prepared to return home to cope with expected stigmatisation there.²⁰

Counselling for leprosy patients in Thailand has been done only in some health units, such as the outpatients department of the National Leprosy Organisation, and in some regional and provincial health units. There is no evidence to show to what extent it has helped to reduce stigmatisation.

Discussion

The impact of stigma on the effectiveness of leprosy control programmes has been increasing recognised. This has fuelled efforts to deal with stigma.

Integration of leprosy programmes into the general health care system is an essential part of the World Health Organization's strategy to eliminate leprosy.²¹ It is considered an approach to promote accessibility of leprosy services for people affected and to reduce stigma related to leprosy. However, not all countries recognise the importance of integration in stigma reduction. For instance, the extent of stigma reduction was not mentioned in the evaluation report of the Thai leprosy programme.^f In India, where an investigation of the results in terms of stigma have been undertaken, there was less self-stigmatisation among leprosy patients and less social stigma in communities with an integrated approach rather than a vertical approach.¹² In mental illness, there is no evidence so far regarding the effect of integration on stigma reduction. However, a study of Mwape in Zambia found that care providers thought that integrating mental illness into primary health care would gradually change the community attitude as community members see that mental patients are cared for and recover, rather than them being locked away.

^gRaj PrachaSamasai Institute. Proceeding of the meeting on how to solve delay in diagnosis at the hotel in Chiangmai on 22 December 2003.

IEC is an approach used in many countries to raise the general population's awareness of leprosy in order to encourage early reporting and diagnosis of the disease. The social marketing campaign done in Sri Lanka is an example of a successful intervention.¹³ The Sri Lanka IEC approach was adapted to promote early treatment and reduce stigmatization in India and Bangladesh. As a result, the stigmatising attitudes towards people affected by leprosy decreased dramatically.¹⁴ Education messages also appear to have been successful in Uttar Pradesh, Madhya Pradesh, Orissa, Bihar and West Bengal, India, and in Bangladesh. In one case, the proportion of people who would not eat food prepared by leprosy patients decreased from 68% to 50%, and the proportion of people who would not buy goods from a shopkeeper known to have leprosy decreased from 78% to 25%.¹⁴ However, in some cases, IEC did not succeed as expected. A study in South India revealed that knowledge about the cure of leprosy did not change negative attitudes towards leprosy patients, possibly because fear of leprosy militates against attempts to educate the public on facts of the disease.^{14,22} The reason that the attitude remained unchanged may be that this study did not take the beliefs of the target group regarding leprosy into consideration, while the successful social marketing approach did. In the Sri Lanka approach, before launching IEC, community-based surveys on knowledge, attitudes and practices on leprosy were undertaken, together with focus groups to explore perceptions of leprosy. This information was used to develop targeted IEC materials. According to Dalal, 'an attitude is a complex system of interrelations among three components: beliefs (evaluation), affects (feelings) and behaviour tendency. To understand disability attitudes, it is essential to take all three into consideration, where change in one component will affect the overall attitude.'²³

Another success factor related to IEC is combining IEC with other activities. In the Sri Lanka approach, they also trained health workers to diagnose leprosy and refer persons with suspicious lesions to the leprosy staff. They improved the network of clinics. This approach is consistent with the recommendations of Bollinger who studied stigma associated with HIV/AIDS.²⁴ He suggested that IEC should be considered as one component of stigma reduction interventions, but that IEC would not be adequate independent of other strategies.²⁴ Successful outcomes may be reached if interventions also include strategies to address issues of physical access, interpersonal communication and the involvement of the community.¹³

The IEC intervention also has to be tailored to the target area and group as recommended by Dijker & Kooman. They argued that interventions aiming to reduce stigma should be tailored to the type of condition, type of society and type of individuals involved.²⁵ These factors determine the major motivational systems that affect people's responses to perceived deviance.

SER is another type of intervention that has been launched to reduce stigma. In Nepal and Nigeria, SER has been reported as being successful in helping people affected by leprosy regain their dignity by involving them as participants in SER.¹⁷ This resulted in positive attitude changes in the community and reduced internalised stigma of people affected by leprosy.¹⁷ SER can also positively affect stigma related to other health conditions, effectively changing community attitudes. A CBR project was launched in Allahabad District, India, which included socio-economic development and social integration of people with disabilities.²³ Attitudes towards people with a physical disability changed because the social changes created dissonance by demonstrating strengths of persons with

disabilities who had previously been looked down upon as unproductive members of the community.

Changing the name of the disease and counselling are other strategies aiming to reduce stigma.^{19,20} To date, there have been no reports of their effectiveness.

In conclusion, interventions with at least some evidence of success in reducing stigma are the integration of a leprosy programme into general health care, and IEC and SER interventions. To collect additional evidence of the effectiveness of the interventions, particularly where the leprosy programme has already been integrated into general health care, stigma should also be included in programme evaluation objectives. IEC interventions should be preceded by careful study of the target area and population. They should be combined with other stigma reduction strategies to achieve an optimal effect.

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